

### III. A National Perspective

**There is no uniform** or standard approach to providing services and supports to individuals with a developmental disability in the United States. Each state, based on historical experience, has developed its own unique system and, very often, the criteria they use to determine eligibility for developmental disabilities services and the level of services and supports provided.

As the map in Figure 1 illustrates, a majority of states have broadened their definition for service eligibility to include not only individuals with mental retardation but also those with other types of disabilities. Moreover, a majority of states have designated one agency as the responsible entity for coordinating and providing services to a more extensive developmental disabilities population.

*Figure 1.*

#### **NATIONAL PERSPECTIVE**

##### ***How States Organize DD Services***



Only Connecticut, Massachusetts, Pennsylvania, Virginia, Alabama, and Mississippi have a state agency that serves only people with mental retardation.

About 39 states use eligibility criteria that mirror the federal definition of developmental disability, although some exclude individuals who do not have a cognitive disability (*i.e.*, persons who have only a physical disability are not eligible for the state developmental disabilities services). Three states limit developmental disabilities agency services to persons with mental retardation or autism, and two require the presence of either mental retardation or significant limitations in both intellectual functioning and adaptive behavior.

The introduction of eligibility criteria that are more inclusive than just mental retardation therefore represents the national norm. Connecticut's practice, in this regard, is the exception rather than the rule. It should be noted, however, that information obtained from sample states strongly suggests that expanding eligibility – that is, moving to

a broad developmental disabilities definition - has not necessarily been accompanied by commensurate funding increases. This has resulted in situations where services and supports are not available in all areas, leading to inconsistent access and a lack of services for eligible citizens.

Thus, across the country, while it is becoming accepted practice for developmental disabilities services to be managed within a single state agency, “lessons learned” strongly suggest ***it is critical to provide enhanced funding and resources if the change is designed to actually make a difference*** in the lives of people. See Appendix B for a copy of the committee report.

## IV. Services in Connecticut

**A thorough analysis** of services and supports in Connecticut was conducted by the State Level Services Committee. They surveyed state agencies and interviewed agency representatives to develop a comprehensive description of what is currently available for citizens with developmental disabilities, who do not have mental retardation, as defined in section 1-1g of the general statutes. The result, which is summarized in a series of figures that follow, illustrates a complicated, fragmented, and confusing system that consists of an array of services and supports funded or provided by multiple state agencies. Access to this array of services is based on a series of eligibility requirements, “program-specific” criteria for supports, and numerous funding streams, rather than on the individual and his or her needs and preferences.

A copy of the analysis completed by the State Level Services Committee can be found in Appendix C.

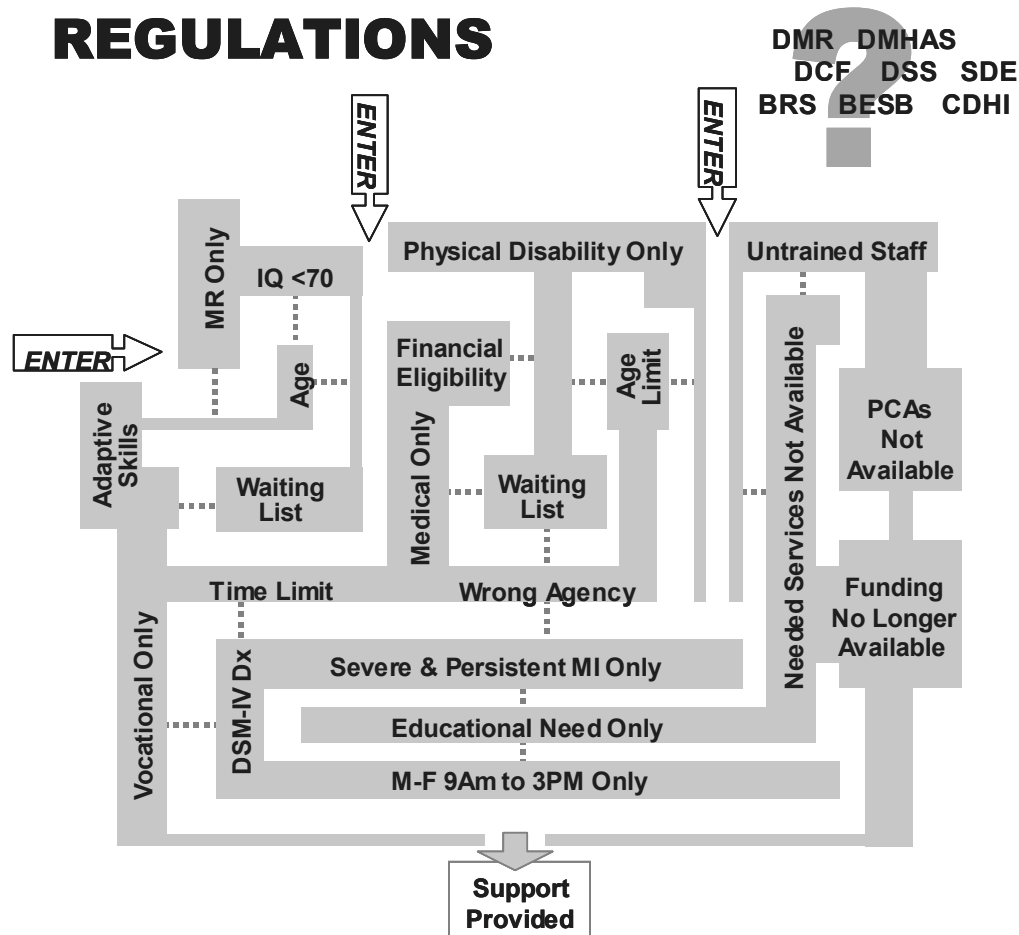
*Connecticut does not have a principal state agency with authority and responsibility for providing or funding services and supports to people with developmental disabilities*, with the exception of those who have mental retardation, as defined in section 1-1g of the general statutes.

Therefore, individuals with developmental disabilities, and their families, are often forced to try to navigate an intricate and confusing maze of rules, regulations, eligibility criteria, and, sometimes, conflicting recommendations from state agencies. Furthermore, even when an individual is successful in accessing all the potential supports he or she may be eligible for, services may be time-limited and staff and programs are often unable to address the most important and pressing needs of the individual or family.

The current “system” of services and supports for people with a

developmental disability other than mental retardation is a ...

## CONFUSING MAZE OF RULES & REGULATIONS



Such a “maze” creates artificial barriers to accessing needed services and supports, resulting in citizen frustration and haphazard access to services. The lack of a standardized or coordinated system of service also significantly compromises the state’s ability to generate meaningful data and engage in important planning activities regarding future resource needs.

Additionally, different state agencies have responsibility for providing services and supports based upon the age of the individual (i.e., responsibilities differ for children and adults). This in turn creates a need for multiple transitions from one service agency to another, leading to further confusion and gaps in service.

## *Services for Children*

As noted earlier, Connecticut's human service system is a complex maze. Figure 2 provides a snapshot of this complexity and the large number of footnotes illustrate the intricacies involved in not only understanding eligibility but also in securing services. The nature of Connecticut's service system makes it impossible to provide a simple illustration without including multiple qualifications.

At the time of this writing, the State Level Services Committee identified the following agencies as funding or providing some type of service for children and youth with developmental disabilities 3 – 17 years of age, who do not have mental retardation, and their families: (a) the Board of Education Services for the Blind (BESB), (b) the Commission on the Deaf and Hearing Impaired (CDHI), (c) the Department of Children and Families (DCF), (d) the Department of Public Health (DPH), (e) the Department of Social Services (DSS), and (f) the State Department of Education (SDE) through the Local Education Agencies (LEAs).

It should be noted that these agencies also serve children who do not have developmental disabilities and some of the agencies may also serve adults.

### **STATE AGENCIES SERVING CHILDREN**

<b>BESB</b>	<i>Bureau of Educational Services to the Blind</i>
<b>CDHI</b>	<i>Commission on Deaf and Hearing Impaired</i>
<b>DCF</b>	<i>Department of Children and Families</i>
<b>DMR</b>	<i>Department of Mental Retardation</i>
<b>DPH</b>	<i>Department of Public Health</i>
<b>DSS</b>	<i>Department of Social Services</i>
<b>SDE</b>	<i>State Department of Education</i>

While there are several agencies that provide services to some children and youth with developmental disabilities, **access to these state services and supports is limited by a number of eligibility criteria and characteristics.**

These can include: (a) diagnosis, (b) family income, (c) severity of the disability, (d), commitment to DCF, or (e) agency resources. For example, family income and assets (i.e., a means test) limit access to programs and services such as Medicaid or food stamps. Other **services and supports are categorical in nature and access is limited to children within a specific diagnostic category** (e.g., special health care needs). Lastly, **agencies have finite resources** (e.g., budgets, personnel) and this characteristic serves to limit the amount of services that any given agency may be able to provide to a child and his or her family.

Connecticut's service system for children and youth with developmental disabilities 3 – 17 years of age, who do not have mental retardation, and their families can be summarized as follows.

1. Connecticut has no principal state agency that is assigned the role of coordinating and delivering services and supports to children and youth with developmental disabilities, who do not have mental retardation, outside the mandates of IDEA.
2. There are several programs (e.g., MEDICAID, HUSKY) that finance or assist with financing traditional medical care services that are available to all children, whose families meet a means test (i.e., income and assets).

#### **Access to services—**

***“I need a service broker who would act as an advocate to obtain services we need and to cut through the red tape.”***

Focus Group Parent

3. Children and youth with developmental disabilities, who do not have mental retardation and their families do not have the same routine access to services and supports as those children and youth with mental retardation and their families. For example, LEAs are the only agencies that provide services and supports to children and youth with autism spectrum disorders, who have no other disabilities. These services and supports focus on a child's educational needs, are typically offered only during the school day and year, and do not include many family support services such as family counseling, respite, or financial subsidies.
4. Children and youth with developmental disabilities, who do not have mental retardation, and their families do not have the same routine access to services and supports as those children and youth within the child welfare system (i.e., DCF).
5. While not always the case, families, whose children may

qualify for any of the programs or services provided by or through these state agencies, must apply to each agency. In other words, there is no single point of entry or formal mechanism for dealing with applying for multiple programs and services or cross agency service coordination.

#### **Access to training—**

*“What David needs the most is social skills training . . . I can’t seem to get it for him from any source, even being willing to pay . . .*

Focus Group Parent

**Figure 2. A depiction of state agency limitations in regard to providing or funding services and supports to children and youth 3 through 17 years of age with developmental disabilities, who do not have mental retardation, as defined in section 1-1g of the Connecticut general statutes, as amended.**

D = Diagnostic or categorical limitations  
S = Severity of disability limits service  
C = Within the care of the department

R = Resource limits accessibility (e.g., state agency budget, waiting lists)  
I = Income limitation (financial means test)  
A = All

CHILDREN & YOUTH	Agency or Bureau							
Service Category	BESB <sup>1</sup>	BRS <sup>2</sup>	CDHI <sup>3</sup>	DCF <sup>4</sup>	DMR <sup>5,6</sup>	DPH <sup>7</sup>	DSS	SDE <sup>8</sup>
Access (sign language interpreter, Braille)	D		DR	C+D				D
Assessment	D			C or D		ID		D
Assistive Technology	D			C+D		ID	I	D
Case Management	D		DR	C or D		ID	I	
Child Protection				A				
Education (related services, transition)	D			C or D				D
Education & Training: Families/Caregivers	D			C or D		ID		D
Financial Subsidy (cash)							I	
Residential Service (out-of-home)	D <sup>9</sup>			C or D				D
Family Support (respite, cash subsidy)				C or D		ID <sup>10</sup>	IDSR <sup>11</sup>	
Juvenile Justice Services <sup>12</sup>				C				
Health Care Financial Support	D <sup>13</sup>					ID	I	
Health Care Service				C or D		ID		DI
Mental Health Financial Support							I	
Mental Health Service	D		DR	C or D				D
Transportation Services				C or D				D
Recreation Support	D			C or D				D

<sup>1</sup> Must be blind or visually impaired.

<sup>2</sup> Rehabilitation services are sometimes available for 16- and 17-year olds who have left school.

<sup>3</sup> Must be deaf or hearing-impaired.

<sup>4</sup> DCF provides services and supports only to children and youth within their care and/or who have a primary mental health disability (Axis I).

<sup>5</sup> Section 17a-215 of the Connecticut general statutes as amended designates DMR as lead agency to coordinate state agencies that have responsibility for providing services to autistic persons.

<sup>6</sup> DMR provides services and supports only to children and youth who have mental retardation or Prader Willi.

<sup>7</sup> Must meet requirements for Children with Special Health Care Needs.

<sup>8</sup> SDE oversees the services and supports provided through local boards of education. Children and youth must determined "disabled" by the Planning and Placement Team (PPT) under 13 federally identified categories of IDEA. Services are based on the child's needs as delineated in the IEP and are most often provided within the school, during the school day.

<sup>9</sup> As part of an out school district placement as delineated in the IEP.

<sup>10</sup> Up to \$500.00 per year is available for respite on a first comes first serve basis.

<sup>11</sup> To be eligible, children cannot have mental retardation and must be between 5 and 18 years of age. There are currently 27 slots, which are full.

<sup>12</sup> No juvenile justice commitments after 16 years of age.

<sup>13</sup> As they relate to vision services.



## *Services for Adults*

As with Connecticut's system of services and supports for children with developmental disabilities, the nature of the adult service system also makes it impossible to provide a simple illustration without including multiple qualifications. A matrix that outlines services provided by state agencies for adults is presented in Figure 3 and Appendix C contains a more detailed description.

1. Connecticut also has no principal state agency assigned the role of coordinating and delivering services and supports for adults with developmental disabilities, who do not have mental retardation.
2. Individuals with developmental disabilities, who do not have mental retardation, do not have the same access to services and supports as those individuals who have mental retardation or a medical diagnosis of Prader-Willi syndrome.

3. Within budgetary constraints, BRS provides services on a time limited basis and as they relate to employment to individuals with developmental disabilities, who do not have mental retardation.
4. DSS is designated as the lead agency for services to persons with physical or mental disabilities whether or not they have a developmental disability. Of note, are the DSS home and community based Medicaid waiver programs (e.g., ABI, PCA).

### **STATE AGENCIES SERVING ADULTS**

<b>BESB</b>	<i>Bureau of Educational Services to the Blind</i>
<b>BRS</b>	<i>Bureau of Rehabilitation Services</i>
<b>CDHI</b>	<i>Commission on Deaf and Hearing Impaired</i>
<b>DMR</b>	<i>Department of Mental Retardation</i>
<b>DPH</b>	<i>Department of Public Health</i>
<b>DSS</b>	<i>Department of Social Services</i>

**Figure 3. A depiction of state agency limitations in regard to providing or funding services and supports to adults 19 years of age and older with developmental disabilities, who do not have mental retardation, as defined in section 1-1g of the Connecticut general statutes, as amended.**

**D** = Diagnostic or categorical limitations

**E** = Employment and vocational rehabilitation related

**S** = Severity of disability limits service

**R** = Resource limits accessibility (e.g., state agency budget, waiting lists)

**I** = Income limitation (financial means test)

<b>ADULTS</b>	<b>Agency or Bureau</b>						
<b>Service Category</b>	BESB <sup>14</sup>	BRS <sup>15</sup>	CDHI	DMHAS <sup>16</sup>	DMR <sup>17 18</sup>	DPH	DSS
Access (sign language interpreter, Braille)	D	ESR	DR				
Assessment	D	ESR <sup>19</sup>		ID			ISD
Assistive Technology	D	ESR					ISD
Case Management	D	ESR	DR	ID			ID
Education & Training for Individual	D	ESR		ID			
Education & Training for Families/Caregivers	D						
Economic and Cash Subsidy				ID			I
Residential Service (in-home and out-of-home)				ID			ISD
Family Support (respite, in-home support, cash subsidy)				ID			ISD
Health Care Financial Support							ISD
Health Care Service	DE			ID <sup>20</sup>			
Mental Health Financial Support	DE			ID			ID
Mental Health Service	D		DR	ID			
Transportation Services	DE <sup>21</sup>	ESR					ID
Recreation Support							
Vocational	DE	ESR					

<sup>14</sup> BESB provides services and supports to persons who are legally blind.

<sup>15</sup> BRS provides vocational rehabilitation services to individuals with the most severe disabilities.

<sup>16</sup> DMHAS provides services to persons with developmental disabilities only if there is a concomitant psychiatric disorder.

<sup>17</sup> DMR provides services and supports to persons who have mental retardation or Prader Willi.

<sup>18</sup> Section 17a-215 of the Connecticut general statutes as amended designates DMR as lead agency to coordinate, where possible, the functions of the several state agencies that have responsibility for providing services to autistic persons.

<sup>19</sup> BRS provides assessments services only as they relate to the vocational rehabilitation program.

<sup>20</sup> Available only on an inpatient basis as part of DMHAS state hospital system.

<sup>21</sup> Short term.